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3-27-2020

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“I Already Consented for You” – The Privacy Implications of Consenting to Genetic Family Tree Sites Like Ancestry and 23andMe

Family trees and genealogy books have dated back many decades, and society’s heightened interest in lineage and genetic background is not novel to recent innovations such as Ancestry or 23andMe. However, it is worth noting that these sites have had a steep rise in popularity over the last few years. In fact, Ancestry alone sold 1.5 million DNA kits on Black Friday in 2017.¹ Our interest in who we are at a deeper level makes sense. There are clear cut reasons for knowing where our DNA comes from, such as to predict health problems in the future.² But further, our ancestors’ stories are compelling, sometimes noteworthy. And perhaps we are all searching for a unique connection to our family that belongs solely to our genetic line.³

Given these draws, it is not surprising that so many people have turned to sites like Ancestry and 23andMe, rather than the daunting and extraneous task of researching a family tree the “old fashioned way.” And although many contend that the best way to learn about our genetic line is through talking with our families,⁴ Ancestry has more than 3 million paying members and has more than 15 million people in its consumer DNA network since 2012 alone.⁵ Moreover, it has 20 billion records, 100 million family trees,

¹ Jaya Saxena, *Why You Should Dig Up Your Family’s History – and How to Do It*, THE NEW YORK TIMES, available at <https://www.nytimes.com/2019/02/03/smarter-living/why-you-should-dig-up-your-familys-history-and-how-to-do-it.html> (Feb. 03, 2019).

² See e.g., *Woman uses DNA test, finds sperm donor – and pays a “devastating price”*, CBS NEWS, available at <https://www.cbsnews.com/news/woman-finds-sperm-donor-after-using-dna-test-raising-questions-about-donor-anonymity/> (Jan. 31, 2019).

³ Nathan H. Lents, *The Meaning and the Meaninglessness of Genealogy*, PSYCHOLOGY TODAY, available at <https://www.psychologytoday.com/us/blog/beastly-behavior/201801/the-meaning-and-meaninglessness-genealogy>, (Jan. 29, 2018).

⁴ Saxena, *supra* note 1, (noting that there may be name spelling changes that make researching without family help more difficult).

⁵ *Company Overview*, Ancestry, available at <https://www.ancestry.com/corporate/about-ancestry/company-facts>.

and 13 billion connections.⁶ Using those same numbers, there are 3 million consumers, at minimum, signing the Ancestry privacy policy, thereby allowing their data to be shared.

These types of companies hold massive amounts of consumer data, and they attempt to explain the use of such data through a privacy policy, a written description posted on a website which explains to the user how the company may use, store, and disseminate personal information.⁷ Essentially, if users read the policy, understand it, and agree to the terms, they will use the site.⁸ If not, they will choose not to submit personal information and will therefore cease use.⁹ However, some studies have shown that users are not even clicking on the privacy policies, and even less are basing a decision to use the site on the policy.¹⁰ Nevertheless, Ancestry requires users to agree to the policy when they create their account,¹¹ or at the very least, hold themselves out as agreeing.

Even more concerning is that Ancestry's privacy policy addresses only the person creating the account. In addition, Ancestry's privacy statement provides a warning to users, stating, "You may discover unexpected facts about yourself or your family when using our services. Once discoveries are made, we can't undo them."¹² Nowhere in the privacy statement does Ancestry address the privacy implications of the family members that may be "discovered."

⁶ *Id.*

⁷ Corey A. Ciocchetti, *E-Commerce and Information Privacy: Privacy Policies as Personal Information Protectors*, 44 AM. BUS. L.J. 55, 68 (2007).

⁸ *Id.*

⁹ *Id.*

¹⁰ *Id.* (citing Joseph Turrow, *Americans and Online Privacy: The System is Broken: A Report From the Annenberg Public Policy Center of the University of Pennsylvania* 3 (June 2003); Harris Interactive and the Privacy Leadership Institute, *Privacy Notices Research: Final Results 2* (Dec. 2001), available at <http://www.ftc.gov/bcp/workshops/glb/supporting/harris%20results.pdf>).

¹¹ *Your Privacy*, Ancestry, available at <https://www.ancestry.com/cs/legal/privacystatement>, (Dec. 23, 2019).

¹² *Id.*

Consider for a moment that identical twins, with identical DNA, may produce the same results under an Ancestry DNA Profile. Let's say that Twin #1 consents to the privacy policy when they create their account, but Twin #2 reads the policy and determines that they do not want their data shared so they elect not to provide a DNA sample. Many would argue that identical twins are not necessarily guaranteed to have an identical result through these DNA sites.¹³ And while that may be true, many doctors and experts have found the concept of twins receiving different results to be "mystifying."¹⁴ Many experts have even gone so far as to say that identical twins should have identical results if using the same DNA company because the raw data collected from twins' DNA is nearly exactly the same, even "shockingly similar."¹⁵ Under this theory then, the data from the twin who did consent and provide a sample will still be shared. In this case, doesn't Twin #1 technically consent on behalf of Twin #2?

Now consider situations in which sperm donors intend and wish to remain anonymous. Years later, a family member of the sperm donor signs up for Ancestry and submits a sample for varying reasons. Instead, Ancestry notifies them that they have a match, and this match, is a child conceived from the sperm donor, their relative's, sperm. This situation, although possibly alarming, is not all that farfetched in using these sites. In at least one instance, a woman created a DNA test from 23andMe for her five-year old daughter, one of thousands of children conceived with sperm from an anonymous donor.¹⁶ The woman wanted to know more about her daughter's ancestry and possible health

¹³ See e.g., *Twins get some 'mystifying results when they put DNA ancestry kits to the test*, CBC NEWS, available at <https://www.cbc.ca/news/technology/dna-ancestry-kits-twins-marketplace-1.4980976> (Jan. 18, 2019).

¹⁴ *Id.*

¹⁵ *Id.*

¹⁶ CBS, *supra* note 2.

issues, but she ended up with a lot more than she bargained for.¹⁷ One of the anonymous donor's immediate relatives had appeared as a result, and the relative was listed as open to messaging.¹⁸ The woman reached out explaining the situation, prompting the relative to reply that they did not understand.¹⁹ But soon after, the woman was served with a cease and desist order, telling her not to contact the anonymous donor or learn any more information about his identity or background.²⁰ These outcomes are not necessarily unique to this case, and experts have said that in 2019, this type of uninvited contact may even be "unavoidable," noting that it is "impossible to promise anyone anonymity anymore."²¹ What is concerning is that the anonymous donor himself did not sign up for 23andMe and thus did not consent to the privacy policy. Instead, a close relative did, and their DNA was similar enough to his that it was shown as a potential match to this five-year old. Did this relative effectively consent on behalf of the anonymous donor for his DNA to be on this site?

Finally, consider an instance in which an organ or blood donor's DNA is detected in the recipient's blood for years after a transplant occurs.²² In one instance, a woman took an Ancestry DNA test intending to discover her own background. But her DNA exactly matched that of a young man in New York.²³ One might question how this is possible. The New York man was the anonymous source of an umbilical-cord blood transplant to treat

¹⁷ *Id.*

¹⁸ *Id.*

¹⁹ *Id.*

²⁰ *Id.*

²¹ *Id.*

²² Sarah Zhang, *A Woman's AncestryDNA Test Revealed a Medical Secret*, THE ATLANTIC, available at <https://www.theatlantic.com/science/archive/2019/09/woman-cord-blood-donor-dna-test/597928/> (Sept. 13, 2019).

²³ *Id.*

the woman's non-Hodgkin's lymphoma nearly two decades ago.²⁴ His cells became her cells, and those cells are the ones picked up by the ancestry test.²⁵ We must again consider whether her use of Ancestry circumvented the need for consent from the New York man to have his DNA to be included on the site. For nearly thirty years, donations from infant umbilical-cord blood were strictly anonymous, but now, with sites such as Ancestry's DNA testing, this policy has been worked around, regardless of whether the donor ever consented.²⁶

In all of these examples, someone else has effectively consented on behalf of another person. By submitting one's DNA to Ancestry, Ancestry has the ability to provide information, secrets, and surprises based on others who share genetic links. Although these sites have warnings and privacy policies that must be accepted before using the site, these policies only seek the consent of the individual providing the sample. They do absolutely nothing to protect or otherwise inform others whose privacy would be violated by the release of the DNA test results.

Although many would maintain that Ancestry and 23andMe likely provide more benefits than risks to users and these situations are exceedingly rare, we must consider whether these DNA sites are doing enough to protect unwitting family members who did not agree to the privacy policy. It would be impossible to require the consent of all people who may be affected by the DNA matches or information because this would include children who have yet to be born, as well as family members who are unknown to even the person providing the sample. But perhaps these DNA sites should be held accountable to

²⁴ *Id.*

²⁵ *Id.*

²⁶ *Id.*

warn users of these risks. Sites like Ancestry and 23andMe should be informing users of the concept of providing consent on behalf of other people that are both known and unknown to them that may share a genetic link. And this information must be through a clearer and more concise avenue, not as a one sentence warning in an already long and confusing privacy policy.